

Flynn, Eileen

From: Elaine Burns <elaine@theburnsteam.net>
Sent: Tuesday, February 10, 2015 10:02 AM
To: HSTestimony
Subject: Proposed H.B. No. 6155 AN ACT CONCERNING THE MEDICAID WAIVER APPROVAL PROCESS.
Attachments: HB6155 testimony.docx

This is my testimony regarding HB 6155, I have also attached a link, thank you - Elaine Burns

Senator Moore, Representative Abercrombie and Members of the Human Services Committee,

My name is Elaine Burns, I am the mother of brain injury survivor Ryan Cornell, who was injured 18 years ago, at age 18, and has been on the ABI Waiver for approx. 17 years.

I am also the President of CT Brain Injury Support Network, and former President of the Board of BIAC, I also currently serve as a member of the ABI Waiver Legislative Advisory Committee. I have been a strong advocate for brain injury survivors for many years, and am passionate about doing so as a way to give back for all the help and support I have received over the years.

I support Bill No. HB6155 and specifically the guidelines to notification that I have submitted in writing below.*

The need for this Bill is significant, although I appreciate the efforts of legislators to ensure existing waiver programs remain intact, that is not what is actually occurring. DSS continues to make changes, with little to no notification or input from those directly impacted, the changes impact those on Waiver I and II. The most recent change we only found out two days prior to the Public Hearing. The change was passed and I have to wonder if more stakeholders had attended and voiced their concerns if the outcome would have been different.

Once the change was passed, DSS wasted NO time informing families and survivors that if they did NOT:

- Take on the liability and risk of becoming employers.
- Become liable for workman's compensation claims - unless they could spend thousands of dollars on a workman comp insurance policy (\$5,000 was the average quoted cost per year)
- Sign paperwork that included a Power of Attorney form and other complex paperwork.

If they did not comply, they were told their loved ones staff would no longer be paid as of Jan. 1, 2015, they had to quickly choose between fear of change in services and LOSS of services! The timeframe was too short for any other realistic options. Most families signed the paperwork, but are still struggling with the aftermath, which for some survivors has caused a loss of services due to staff leaving the programs.

Do any of us feel they could have, after knowing this change was imminent for more than a year, done this in a better, more timely manner?

I am now being told, as are others, that DSS has more big changes ahead for us, but we continue to "learn" of potential new changes in an informal manner from DSS Social Worker's and other contacts. We have no information or announcements from DSS about impending changes and I am left to wonder when DSS will notify us, or will we, yet again, accidentally find out two days before a Hearing...IF there is a Hearing?

We need your help to change this process, thank you.

*HB 6155

I support the following:

1. Notification of proposed changes at least two months prior to a Public Hearing, notification via email and snail mail to participants conservators and providers.
2. Major changes such as termination or massive overhaul of a program will require a Public Forum prior to holding a Public Hearing to gauge the public response and to give Legislators time to gather further information if there is strong opposition from stakeholders.
3. Public Comments allowed during the first 30 days after notification of changes is sent out.
4. No less than a 10 day notice (email and snail mail) of Public Hearings on changes.

Respectfully,

Elaine Burns

Mom of Brain Injury Survivor Ryan Cornell

President

CT Brain injury Support network

CTBISN@Live.com

860-655-4688

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